

Senator Terry Gerratana, Co-Chair  
Representative Matt Ritter, Co-Chair  
Senator Joe Crisco, Vice-Chair  
Representative Emmet Riley, Vice Chair

Good Afternoon, Senator Gerratana, Representative Ritter, Senator Crisco and Representative Riley

I am testifying today in support of SB918 an Act concerning the provision of services to individuals with intellectual disability, which would require the Department of Developmental Services to provide certain services to all individuals with intellectual disabilities.

My only son will be 26 next week. His diagnosis is autism, and his disabilities resulting from that are severe. He uses single words to express concrete needs (bread, pretzel), has no sense of safety, doesn't realize that sometimes he must stop eating, can't make reasonable food choices. He lives largely in the present, which means that it's really difficult, if not impossible, to change behavior that doesn't work for him.

I've testified about him before and I continue to try to find the words and examples to help you understand what our lives are like. I've read that it takes a village to raise a child. That is especially true with mine. Our little household consists of Robert and me. Providing 24 hour support and supervision for an adult is not a job for one person alone. No one has that much energy. I can keep my son safe, and I can keep him happy, but not usually both at the same time. This is why I rely on the services provided by DDS to help keep him happy and safe. He attends a day program funded by DDS, and he receives funds to pay a respite care provider. These are very important services to our small family, and if they are cut, life will be harder than it currently is

He isn't enough of an emergency to get a residential placement, even though he has been on the waiting list since before his father died 10 years ago. I'm his only caregiver. I must make sure that he is cared for at every moment of every day, because I can't trust him to cross the street, or handle any household emergency. It requires the same commitment that caring for a newborn baby demands. But he is 6 feet tall, and I am not the young mother I was once. It is my nightmare to be the little old lady with osteoporosis, barely able to negotiate the supermarket, but being there with my strapping son at my side, asking for more bagels.

I make it work for Robert and for me by patching together a very thin quilt of assistance. And when a rip appears in that quilt, which often happens, our daily life is disrupted. I wanted to testify in person today, but Robert's respite caregiver is unavailable. I only work part time, because day program hours do not stretch to allow me to be out of the house as long as I would need to hold a responsible, full time job.

And someday I'm going to die too and there will be no one to care for him except DDS. And they won't know how to care for him because they won't be familiar with him, in spite of my best efforts. Robert deserves better, and so does his peer group—other adults whose disabilities get in the way of them living their best lives on their own.

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